Healthy Active Living in Youth With Neuromotor Disability (HALYNeD) Project: A Translational Project With Researchers, Pediatric Physical Therapists, and Patients Working Together Toward Evidence-Based Exercise Prescription

BACKGROUND

While children who are healthy are already at risk for a hypoactive lifestyle in this modern society, this is even more the case in children with chronic disease or disability.[1] Next to general health risks, low fitness levels may contribute to fatigue and lower levels of activities and participation.[2] In the Netherlands, several groups are working on interventions to improve fitness and daily physical activity in children with childhood disability and chronic disease.[3]

This current project was initiated in 2011 by the Research Group Lifestyle and Health at HU University of Applied Sciences—home to both undergraduate and master programs for Pediatric Physical Therapy—and the Child Exercise Center at the Wilhelmina Children's Hospital. These 2 organizations are housed at the same campus and have joint interest in exercise and health.

HALYNeD

Out of these encounters emerged 2 topics for future research (for now confined to 2 patient populations): (1) which factors are important in (promoting) participation in daily physical activity among children with spina bifida (SB) and children with muscular dystrophy (MD) and (2) development of exercise testing for children with SB who are wheelchair dependent and children with MD who are ambulatory. A consortium was then formed consisting of the HU University of Applied Sciences (project leader site), the Child Development and Exercise Center, the foundation Fitkids, rehabilitation center De Hoogstraat, and the Dutch Association for Pediatric Physical Therapy (acronym: NVFK). Funding was received through SIA RAAK, a program of the Dutch Ministry of Education, Cultural Affairs and Science designated for applied research involving both research and professional organizations.

Participation of Patients and Pediatric Physical Therapists (PPTs)

In the first year, qualitative research methods were applied to gain more information regarding participation in physical activity (Bloemen et al., in progress). This was done in order to make sure research questions were in line with both patients' needs and those of PPTs. Next to ensure clinical relevance of the project, active input of PPTs and patients will likely facilitate the transfer and implementation of newly gained knowledge and skills.

Research Projects

Based on the first year, research projects were further specified. This resulted in several projects we're currently undertaking:

Let's Ride Study: This study aims to determine the relationships within and between several aspects of fitness, activity, and participation in children with SB who are wheelchair dependent. At the same time, valid, reproducible, and feasible protocols will be developed to measure aerobic performance, anaerobic performance, functional wheelchair riding, and physical activity in children with SB who are wheelchair dependent.

Exercise Testing in Children With Muscular Dystrophy: This is a pilot study looking at the feasibility and safety of maximal exercise testing in children with Duchenne or Becker Muscular Dystrophy.

Physical Activity Needs/Questions in Children With (Neuro)Muscular Disease: This is a descriptive study looking at physical activity in children visiting "Spieren voor Spieren" children's center ("Muscles for muscles," a specialized center for diagnosis and treatment of children with muscle disease).

Best Practice Advices: These are several student projects in which PPT students are summarizing best

Fig. HALYNed Skills Lab. This figure is available in color in the article on the journal website, www.pedpt.com, and the iPad.

practice for testing and improving physical fitness and physical activity for children who are wheelchair dependent. This best practice is based on literature, current practice, and interviews with both PPTs and other experts.

From Research to PT Practice

Results from the research are being presented at both annual meetings of the patient organization as well as during annual symposia organized by the HALYNeD partners, consisting of both scientific lectures and skills labs (see Figure). At the same time, several partners also play important roles in (jointly) publishing in peer reviewed journals,[4-7] writing national guidelines, writing chapters for a pediatric physical therapy book, and presenting at international conferences. Last but not least, our future colleagues, now students at the pediatric physical therapy school, are participating in HALYNeD as research assistants, preparing them early in their professional development for evidence-based practice.

Fit for the Future?

We aim to receive funding for creating an interactive Knowledge Transfer System called "Fit for the Future" to support PPTs in their clinical reasoning and facilitate implementation of interventions to improve physical fitness and physical activity in children with childhood disability and chronic disease. At the same time, this system would enable us to jointly develop and evaluate interventions within the PPTs' practices.

Want more information? E-mail janke.degroot@hu.nl or check out our (Dutch) website: halyned.hu.nl.

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The authors declare no conflicts of interest.

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